



the compassion to care, the leadership to conquer

**Committee on Public Health
Wednesday, February 20, 2013**

Written Testimony of **Laurie Julian, Director of Public Policy, Alzheimer's Association**, CT Chapter (The Association) in support of **H.B. 5979 *An Act Establishing a Task Force on Alzheimer's Disease***

Senator Gerratana, Representative Johnson and distinguished members of the Committee on Public Health, thank you for allowing me to submit testimony on behalf of the Alzheimer's Association, CT Chapter.

The Alzheimer's Association is a donor supported, non-profit organization serving the needs of families, health care professionals and those individuals who are affected with Alzheimer's disease and related dementias. The Association provides information and resources, support groups, education and training, and a 24 hour, 7 day a week Helpline.

Introduction

In Connecticut, there are over 70,000 citizens with Alzheimer's or other related dementia.ⁱ This is projected to escalate rapidly in coming years as the baby boomer generation ages. Alzheimer's disease is the sixth-leading cause of death. In fact, among the 10 leading causes of death, it is by far the fastest growing – increasing more than 50 percent from 2000 to 2007.

Alzheimer's is the only disease in the top 10 causes of death without a way to prevent, cure or even slow its progression. But beyond the human impact on families, the economic burden is staggering, with total care costs nationally escalating from \$183 billion to more than \$1 trillion by 2050.

Individuals with Alzheimer's disease and other dementias are high users of health care, long-term care and hospice services and are most at risk of nursing home transition. This has significant financial implications for state budgets. Average per person Medicaid payments for Medicare beneficiaries with Alzheimer's and other dementias are nineteen times as great as average Medicaid payments for Medicare beneficiaries without the disease.ⁱⁱ People with Alzheimer's disease and other dementias use state

dollars to pay for their health care, especially long-term care. About half of all Medicaid beneficiaries with Alzheimer's or another dementia are nursing home residents. Among nursing home residents with Alzheimer's disease and other dementias, just over half rely on Medicaid to help pay for their nursing home care.

There are more than 174,000 caregivers, usually family members who provide unpaid care for someone with the disease, often compromising their own health. Alzheimer's and Dementia caregivers provide over \$2.4 billion in uncompensated services and endure significant emotional, physical and mental stress, multiplying the overall cost of the disease.ⁱⁱⁱ Sixty-one percent of caregivers for people with Alzheimer's or other dementia rate the emotional stress of caregiving as high or very high, and are more than twice as likely as caregivers of people without these conditions to say the greatest difficulty associated with caregiving is that it creates or aggravates health problems.^{iv}

Currently, 26 states have published a State Alzheimer's Plan. Fifteen states have established task forces to develop a State Alzheimer's Plan and are in the process of writing plans (see attached map).

Alzheimer's Disease Task Force

The bill would create a task force and bring together an array of stakeholders: state agencies, legislators, residential and community care providers, professionals and family caregivers and persons with Alzheimer's disease. Using this approach, state government and private industries can address the Alzheimer's epidemic with a thoughtful, integrated and cost-effective approach, and provide a mechanism to consider pertinent issues from early detection to end-of-life care.

State Alzheimer's Disease Plans

The burden this devastating disease is placing and will place on state budgets, long term care infrastructure and the health care system is enormous. While only 7% of the Medicaid population receives long-term services and supports, 61% (\$2.863 billion) of the FY '12 state budget Medicaid expenditures of \$4.714 billion, were made on the behalf of long-term care beneficiaries. States must not only deal with today's crisis, but prepare for the worsening crisis of tomorrow.

State Government Alzheimer's Disease Plans create the infrastructure and accountability necessary to build dementia-capable programs for the growing number of people with the disease. These plans also prepare states to address a range of issues, including: quantifying the number of individuals with Alzheimer's, availability of diagnostic services across the long term care continuum, building and expanding workforce capacity, and improving dementia care and competency of primary care providers and direct care providers, Medicaid coverage of long-term care for people with Alzheimer's, availability of home and community-based resources and respite care to assist families, and safety of individuals with Alzheimer's who wander, are a few but not all of the encompassing challenges. In sum, a comprehensive state strategy to address

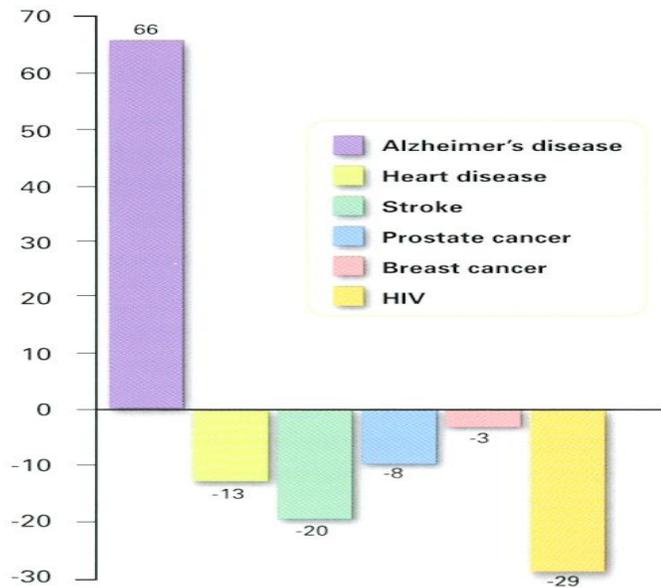
the needs of individuals with Alzheimer's disease provides a mechanism to consider all of these issues collectively.

Most completed state plans contain an executive summary, an overview of Alzheimer's as a public health and a long-term care crisis, an inventory of existing services and service gaps, and a list of policy recommendations to address needs of persons with Alzheimer's disease and their caregivers, and plan for the impending influx of consumers of state funded long-term care services, whether in community or residential settings.

This disease will place an ever-increasing financial, emotional and medical burden on our state and its residents. This is why the The Association supports passage of HB 5979 to create an Alzheimer's disease Task Force to examine the impact of the disease on Connecticut and present a plan for responding to the growing number of individuals with Alzheimer's. Thank you for the opportunity to submit this testimony.

Please feel free to contact me at ljulian@alz.org, or (860) 828-2828.

Percentage Change in Selected Causes of Death, 2000-2008



Source: National Center for Health Statistics. *Deaths: Final Data for 2000 and Deaths: Preliminary Data for 2008*

ⁱ 2012 Alzheimer's Disease Facts and Figures report at alz.org/facts.

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^{iv} The Council of State Governments, *Alzheimer's Disease and Caregiving*, Sept 2011.